

Parent Time

A Newsletter for MoSPIN Parents

Volume 20, Issue 2

October 2015



Greetings!

The focus of this Parent Time newsletter is **taking care of yourself**. Those of you who responded to an earlier parent survey chose this as one of your top themes for our newsletter this year.

We have four MoSPIN families who will be sharing their thoughts and experiences regarding taking care of yourself. Jonie Wilson, Claudia Hall and Aleta Jenson are returning to share their families and their ideas in this issue. In addition, Amanda McKee will share her ideas and her family for the first time. We'll also include some articles and links to resources regarding taking care of yourself and even share a few inspirational quotes.

So - take a moment, sit down, grab a cup of coffee or tea or a bottle of water, relax and do something for yourself (yes!) by reading this issue of your Parent Time newsletter.

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*"Taking care of me means people in
my life get the best of me, rather
than what's left of me."*



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Taking Care of Yourself

By Claudia Hall

Claudia Hall is the mom of Nicodemus, a 2.5 year old with quadriplegic CP (Cerebral Palsy), CVI (Cortical Vision Impairment), hearing impairment, epilepsy, feeding issues and so forth. When not at Cardinal Glennon Children's Hospital, they live in St. Louis.

Like many of you, when I heard the topic of this article, I laughed. My days start too early and end too late, and I feel guilty for taking time to myself when there are so many things my son needs done. Right now we are in the hospital, so things are even crazier than the usual crazy. So some days I'm better at this stuff than others. And that is OK.

Things I do to take care of myself, from instant, in-the-moment to long term things:

Breathe. Deep breath in, hold it, let it way out. I'm not terribly good at remembering to breathe deeply, but when I realize I'm tense, two or three breaths can go a long way toward relaxing.



The minute timer. When my son was first diagnosed, I went to a grief counselor and she gave me a one minute egg timer. She wanted me to use it all the time, but I don't. What I have done is place it on my work desk, and when I realize I'm hunched up over the keyboard with pain in my neck and shoulders, I take a breath and flip the timer. Just watching the sand for a minute can help me start to relax a bit. Sometimes, honestly, it makes me more stressed. Because I can't even calm my thoughts for a minute. Which leads into my next point:

Stopping negative self-talk. This is a big one for me. I look around and everyone is more put-together than me, their houses are cleaner, their kids are typical, and so on and so forth. You know what? When I die nobody will put "she had a messy coffee table" on my tombstone. Good wife, good mother, good friend—these all wind up as final words about a person. "Always had her hair in place" does not. So when I get on these negative self-tangents, I go back to the breathing and acknowledge that I am not perfect, but that I am good enough.



Five minute yoga. There are videos on YouTube that are right around five minutes. Sure, a 90 minute yoga practice is awesome, but five minutes is better than nothing. I try to do it right before bed, and try not to get down on myself when I don't.

The bathroom is my friend. If I don't fold the laundry, or vacuum the living room, I can carve out an hour a week (sometimes) for a hot bath. I lock the door, put earphones in, and soak in hot water until I am a raisin.

I hope one or more of these tips help, but **remember most of all to be gentle with yourself.** Give yourself the compassion you would give another person walking in your shoes.



From the Wilson Family

Hello everyone. I hope you had an enjoyable relaxing summer and are ready for fall and winter. My name is Jonie and my husband and I are a part of MoSPIN because of our son Cheston. We have three children. Andi is 7 and in second grade this year. She had a great summer. She played softball, showed a lamb and a hog at two local county fairs and is now in her fall season of soccer. She keeps us busy and on the go all the time. She is doing very well this year and loves her teacher at school. Clayton and Cheston are our 4 year old twins. Both boys started preschool this fall. Clayton was so excited to go to school. Cheston has been in preschool now since he was three years old. They are in separate



classrooms. I had to make that decision whether to keep them together or separate them and I chose this year to separate them. I do think they miss each other. Clayton played baseball this summer and also showed a lamb and a hog at the fairs as well. He is also playing soccer this fall. Cheston had an equally busy summer. We went camping several times which he loves also. We swam a lot and he got to spend some one-on-one time with his grandma and grandpa which he also loves. He went on his first go-kart ride and he kept yelling "GO FASTER!" The child has no fear whatsoever.

We are a part of MoSPIN because Cheston was born with a very rare genetic disorder called Microphthalmia, aka "Mini Eye Syndrome". Both of his eyes were small so he is blind. He wears prosthetic eyes and has since he was 10 months old. Our daughter Andi has microphthalmia but it only affected her left eye. We are currently in a genetic study through the Albert Einstein Medical Center in Philadelphia, PA. The geneticists are offering support trying to help us with the genetic issue we have in our family. We have been in this genetic study for almost 3 years, and we have not received any news. Since we are a part of the study, we attended the bi-annual iCAN (International Children's Anophthalmia Network) conference this summer in Philadelphia. We drove 17 hours both ways and it was quite the adventure. We had a great time reconnecting with families we have met in the past and meeting new families and friends as well. The kids had a great time and we learned lots of excellent information to help us with our unique family.



This newsletter is about taking care of me and how it applies to my family. I am just going to start out by saying: I am absolutely TERRIBLE at this. When I think about taking care of myself, I think of doing things just for me, going to the doctor for my normal checkups, or doing things with my friends without my kids. This is something that is extremely hard for me and I struggle with it because almost all of my focus is on my family and my work. After that is sleep and sometimes that is even a struggle. I know that sounds terrible but this is something I do need to work on. Just this week, I finally got a hair cut for the first time in eight months and I had to have major dental work done (a root canal) because I had not been to the dentist in five years. But I am working on a plan as to how to make this better.

When John and I had one child life was not too difficult. We went from one child to three children and one who is blind. The first year of my twins' life was a complete blur. I was in survival mode. I was doing well if I made it out the door looking halfway decent, all kids dressed and on time. For two years, the only time I would really get to spend by myself was when I had to go to the store to buy the enormous amounts of diapers and wipes we had to have. Or it was spent in the car traveling for many hours to doctor and ocularist appointments. And I still had to work a full-time job to which I travel 45 minutes one way every day. I will say, my travel time to and from work each day is nice because it is always time I can guarantee as quiet time for me.

Now that the children are older and getting more active and involved in the community, that keeps us busier than when they were younger. I had this perception that when my kids got older and more independent life would slow down for us. I WAS WRONG. I think we are busier now than before, just in a different way. Just this year I have had to really learn to juggle multiple activities and also learn how to say NO to things. We have had to eliminate some activities because life was getting very hectic.

How am I planning on taking better care of me? I do have hobbies and interests but I have not had a chance to enjoy them for so long that the list is very short compared to what it used to be. I enjoy camping, reading, and crocheting. I usually read articles or magazines since a book takes me so long to read because my time is limited. I love to crochet also. I usually do small projects now to get them finished in a timely manner. I am not a huge shopper but I do like to do that occasionally. I always go shopping the day after Christmas. That is my favorite day to shop. I volunteer for the kid's elementary school a lot. I really enjoy this. We do a lot of activities and I have made some wonderful friends through this. Last year I was the official Box Tops counter and counted over 30,000 box tops!

This fall I have started taking classes through the Hadley School for the Blind. They offer multiple courses either in print or online that you can participate in. These courses are free and available for parents, teachers, or family members of visually impaired or blind children. The first course I am in process of taking is You, Your Child and Your Community. It just so happens that one of the lessons in the book is taking care of yourself. How ironic. The next course I am scheduled to do is Intro to Braille. I like this so far. I got the book option instead of online and I usually work on this in the evening. It is not time-consuming and you can do it at your own pace.

One thing John and I do every evening is make sure the kids are in bed by 8:00 pm every night. This not only gives us a chance to spend some quiet time together but it also gives us a chance to do whatever is necessary or we relax and not watch kids' shows on TV. We really do enjoy this time in the evening. John and I will be married for 10 years this spring. It has gone by very fast. We love to spend time together, which we do not get to do very often. The two of us go to Branson for one weekend a year. We have done this the past few years and always enjoy getting away. We also love to go out to eat together, but again this only happens a couple times a year.

I have worked on getting myself in a yearly routine of regularly going to the doctor and I have gone back to the dentist regularly. I know that keeping myself healthy needs to be a priority so I can be around as long as possible for my family. I work hard at keeping my family on a schedule and keeping a daily routine to try to make life go smoother. I have learned that Cheston really needs a routine as well. Even the slightest change in our day can even offset his sleeping which can really have multiple effects for many days. We tend to have bumps in the road, so I think that having a routine helps me deal with these situations and everyday life. The least amount of stress for us is best for me. I really do look forward to the daily little pleasures. I am spoiled in certain ways where I have my necessities that I refuse to give up. One is coffee. I love GOOD coffee. My favorite is Harry & David's Moose Munch coffee. Yes, it is expensive, but it is my daily pleasure so I make sure I get to drink it every morning. Anyone who knows me well knows, do not ask me anything difficult before I have had my coffee.



Taking care of myself is a struggle and I know it will be for a while. My life revolves around my family and my work. For me it is the simple pleasures that keep me going. But I do know it is important to get away from everything and recharge my batteries so I can be the best wife, mother, and person I can be. I hope as the kids get older, I can find more time to do things I enjoy but until then, they will keep me busy and on my toes.



From the McKee Family

Hello MoSPIN families! We are the McKee family, and we are fairly new to MOSPIN. This is our first time to contribute to Parent Time, and we are grateful for the opportunity to share our story with you. My name is Amanda, and my husband Tom and I welcomed our first child in June of 2014. Carter, who is now fourteen months, was diagnosed at four months with CHARGE syndrome. CHARGE syndrome is a very complex genetic disorder that I could spend this entire article talking about. It affects our son in many ways, but with regard to vision he has a condition called micropthalmia. For Carter, this means he is legally blind in his left eye, which is his smaller eye. He has normal vision in his right eye. Carter is also bilaterally profoundly deaf and has bilateral cleft lip and palate. This has been quite a roller coaster year as first time parents as I am sure many of you can relate to.

The topic of this Parent Time is ‘taking care of yourself.’ As a parent of a child with special needs, this can be extremely difficult to do! With any child this is hard, but all the extra attention our special kiddos require always seems to take center stage, leaving little time for ourselves. We all know and hear about the importance, but how does one make it work in our crazy hectic lives? I’m going to share a few things that we have done to help ourselves in this area.

The first way we try to take care of ourselves is by **surrounding ourselves with a good support system**. We are fortunate that we both have family close by, but we have also built strong friendships through our church, jobs, and community groups. As difficult as it is to make time for friends, a good friend can sometimes be just what you need after a difficult day or doctor appointment. We all need people to vent to and share our struggles with. We also need those people who can give us a break for babysitting or be a listening ear over dinner or coffee. We actually have one family that we alternate weekly dinner with. This gives us time to relax, visit, and share our struggles and joys. Plus, I don’t have to cook one night every other week! I

also recently joined a MOPS group. This is a group of moms that I meet with twice a month. Even though they are not moms to children with special needs, I enjoy the time to connect over the typical things my child does. It is an hour away to be refreshed. Investing in friendships is a great way to take care of yourself.

Another way we ‘take care of ourselves’ is by **making memories together**. It is easy to get bogged down with everything there is to do at home. You have your normal household things, plus the giant therapy checklist to try to accomplish. We find that sometimes all that just waits. We take time as a family to have experiences with our son. We go to the zoo, Grant’s Farm, the Science Center. We play at the park, go to story time, walk on trails, go to ball games. It would be easy to say it’s too hard. We have too much to do. But these memories together are the good times that we will remember, provide important experiences for our son, and they keep us sane too! Having fun as a family is an important way to take care of yourself.



A final way we ‘take care of ourselves’ is by **seeking out opportunities to connect with other special needs parents**. We do this a few different ways. One way is through a Facebook group. This allows us to talk to other parents who “get it” in a way that no one else does. We can post specific questions about our child and also post about the milestones and good moments that allow others to celebrate with us. We are also part of a special needs group in our town called Capable Kids. They offer monthly play groups and even parent respite nights. Finally, this year we were able to attend the CHARGE Syndrome Conference. This was an amazing opportunity for us to actually meet other

children with this specific syndrome, as well as their families. We were able to connect with other parents in similar situations and learn the latest research regarding his syndrome. Sometimes I feel as though I'm not researching enough (mommy guilt!), so to be able to have all that information at my fingertips was really nice and put me at peace. Finding ways to connect with other parents of children with special needs helps us take care of ourselves.



In closing, I can't finish this article without mentioning the biggest way that I was able to take care of myself personally this year. My husband and I made the very tough decision that I would not return to my full-time job as a teacher this fall. While it was a very difficult decision for multiple reasons, it has been the best decision for our family. The funny thing is I didn't need to take off to care for Carter. We are fortunate to have my husband's mother who does a great job caring for him. I needed to leave my job for me. The stress of work on top of everything going on with Carter (doctor appointments, therapy appointments, medical difficulties, etc.) was just too much for me to handle. While I felt selfish at the time for taking away income and thus opportunities for our family, it has ended up being the best decision. I am happier and better able to cope with my son's challenges. I know this is not an option for everyone, but I will say it is the biggest way that I took care of myself this year.

Thank you for taking time to learn about our family. Having a child with special needs is one of the hardest things I have encountered in my life. The honest truth is that to stay sane, I have to make a conscious effort to choose joy and focus on the positive in my child. This means forgetting about

the stresses of the unknown or the therapy checklist and learning to enjoy my son for who he is. I can guilt myself and sulk, but that doesn't get us anywhere. Having the right outlook and choosing to focus on what your child CAN do and the joy they bring to your life will allow you to live in happiness. This is one of the best ways to take care of yourself. I hope you are able to take something away from our story.

-Tom, Amanda, & Carter McKee

*"Life is better when
you are laughing."
- Meer Artikeien*

Ten Simple Ways for Parents to Recharge

- Take it outside
- Let go of perfection
- Grow a garden
- Get enough sleep
- Exercise
- Shake things up
- Practice saying no
- Crank up the tunes
- Call a friend
- Claim quiet time

I know – you're thinking, easier said than done! Go to www.understood.org/en/family/taking-care-of-yourself for more information.

From the Jenson Family

Hi everyone! I am Aleta Jenson. My husband Cory and I have five children, Maren (18), Preston (16), Alivia (14), Bethany (13), and Nathias (3). We adopted Nathias in 2012. He was born in San Francisco and has been a wonderful addition to our family. He is such a joy to have in our home. His addition, however, has changed our lives

drastically. We knew that would be the case because we were looking for a special needs child to adopt. Nathias was diagnosed with hydrocephalus before he was born and we knew he would have significant developmental delays. When he arrived and the tests began, we learned that his condition had resulted in multiple brain malformations. This was not unexpected, but then we also discovered his optic nerve hypoplasia. So, yes, we have lots to keep us busy!



Trying to take care of a child with special needs, on top of everything else that needs to be done with four active teenagers in the house, can often feel overwhelming, as I am sure many of you can relate. And trying to take care of yourself? That is easier said than done! Our mornings begin bright and early (sometimes just early) and it is a race to the finish line... one that is often not crossed until well after dark. And did I mention the four teenagers? Sports practices and competitions, marching band rehearsals and competitions, and theatrical rehearsals and performances are interspersed with church activities, therapy appointments, doctor visits, school activities, housework, yardwork, and the list goes on. It can be hard to live a balanced life when you are always running to the next activity.

To be truthful, it's pretty much impossible to achieve balance. Instead, we try to focus on the things that are most important. It has taken some time and practice (and we are still far from perfect)

but we are learning to find ways to take care of ourselves in order to be healthy and happy. And that means not only looking out for our physical needs, but ensuring we are in a good place emotionally as well. If we are too bogged down with worry and stress it often makes us unhappy and affects the entire family. So how do we ensure that seven people with different interests, obligations, and activities are happy? I would like to share a few things we have learned to help us achieve that.

Have a weekly planning meeting: I think the single most important thing we are doing as a family to help take care of ourselves is to have a family meeting at the beginning of each week. When everyone participates in planning what is happening during the week, there are fewer "surprises" and less stress for everyone. Not to mention it makes it easier to get tasks completed because there is a plan for everything. Which leads me to the next point I want to make.

Make sure your planning session carves out some "me time." Even if it is only a little bit, this time can be crucial. As parents (and especially mothers) we are likely to sacrifice our needs to get things done for everyone else. A year ago I started to notice my emotional tank was running on empty. I realized I was allowing myself and others to put my needs dead last on the list of importance. It has taken some effort but I now have one night a week where I am not responsible for taking care of dinner, dishes, cleaning, or bedtime routines. I use the time to work my home business and it is heavenly to have some uninterrupted time to work. I also started taking some classes at the local college to improve my knowledge and skills set. My husband participates in several plays each year with our local stage company for his "me time". He also just started teaching a class at the college that gives him a little extra cash that he can spend on things he would like to purchase or on something fun he would like to do for himself. It also is helping improve himself professionally. In order to have this time for yourself, sometimes you have to rely on others.

Don't be afraid to ask others for help. A great resource for help can be your immediate and extended family members or close friends. We don't live anywhere near our extended family members so there isn't a grandma or other relative to help us. We rely mostly on each other. For the most part this works well. Our older kids help to keep up with the house and yard and they watch Nathias for us from time to time. Since they are busy teenagers they are limited in what they can do. I have had to ask a neighbor to help with Nathias on the night that I have reserved for myself when others can't be around to watch him. That way I still have "me time" to do what I need to while they do what they need to. It's a win/win situation. Other families may need to ask people to help with not just babysitting but with household chores and yard work. Once in a while when our yard work gets really bogged down and we can't keep up we ask members of our church to help us for an afternoon. They are more than willing to help.

Make good use of services in your community. Sometimes paying for extra help just isn't an option. Ask around to find out what kind of resources there are in your local community that may allow you some relief. We now have Nathias in Early Childhood and Head Start. We didn't realize that Head Start has a program set up to allow special needs children into their program who might not qualify otherwise. They have been wonderful. They have hired special assistants to work with him and they incorporate the goals of his IEP into his daily routine as best they can. It is a huge help to us to know that someone else is helping us with his many goals. We have seen a lot of improvement in him this past year. He crawls a little bit now and is climbing furniture. Not to mention he now is seeing well enough that he recognizes objects a few feet away and crawls toward them! We weren't certain that he would ever be able to do any of these things! Perhaps he would have reached all these goals at some point but it has been a lot less stress to have extra helping hands. Another good resource for your family could be as simple as the local gym or YMCA. Often they have play places for young children in a safe environment so the parents can get a work out in or relax

in the pool. The YMCA also has tuition assistance programs for families so your monthly rate is affordable and the child care is often free. We don't have a good program in our current area but we have made good use of the YMCA in other areas we have lived. You may also have respite services available through different programs offered in your area. In our town it is called the Regional Office.

The last thing I want to make sure I stress is to **make sure you schedule in time to do fun things with your spouse and family.** Believe it or not, building our relationships with family members really does help us take care of ourselves too. We become better, happier individuals. We try to include into our schedule some time for a date night every week and time to do something fun as a family. This has become harder to do since we have four teenagers in the house who are extremely busy and sometimes would rather not spend time together as a family. However, building family relationships is a huge piece of good emotional health. If all we do is the mundane, and not take time for our relationships then our relationships become strained and often unpleasant. Thus we become less happy. For some couples, the stresses and worries of a special needs child are immense and divorce is more prevalent than it would be. This can often make life harder than it was before! So plan in some fun! For our family, sometimes it is just a game night. Sometimes it is a cookout, or a night at the High School football game watching the kids perform in the band followed by a trip to Simply Swirled. Other times it is swimming or a picnic at a local state park. One of our family favorites is making homemade frosties and watching the Munsters on Netflix. Don't forget to read together too and schedule time to spend with each child individually. Sometimes other children can feel a bit neglected when another sibling takes a lot of care and attention. So, relax and have some fun!





Taking Care of Yourself

“Self-care does not come naturally to many of us. Remind yourself often that you deserve time for this important task. It benefits you and your child.”

Those wise words are taken from the Matrix Parent Network website. But where do you start? Here are some of their suggestions:

- Get some rest
- Exercise
- Do an activity you enjoy every day
- Eat healthy
- Make and keep in contact with a friend

Find more key points at www.matrixparents.org. Or call their helpline at 800-578-2592.

*“Take time to do
what makes your soul happy.”*
– Emily Quay

Four Ways to Deal with Stress

The American Heart Association shared good advice regarding techniques for managing stress.

1. **Use Positive Self-Talk** – Try to move from the negative to the positive. For example: Change from : “Everything is going wrong “ to “I can handle things if I take one step at a time”
2. **Use Emergency Stress Stoppers** –Examples are: count to 10 before you speak, take deep breathes, say “ I’m sorry” when needed, go for a walk, meditate or pray.
3. **Find Pleasure and Feel Good** – Some examples are: Read a book, play a sport, meet with

friends, listen to music, take a nature walk, play a game.

4. **Calm Your Mind and Body Through Daily Relaxation** – Calm your tension with yoga, tai chi, deep breathing, reclining and closing your eyes, going to your “happy place” in your mind.

Read the complete article to find additional examples of their techniques at www.heart.org.

*“Nothing is impossible. The word
itself says I’m Possible.”*

– Audrey Hepburn

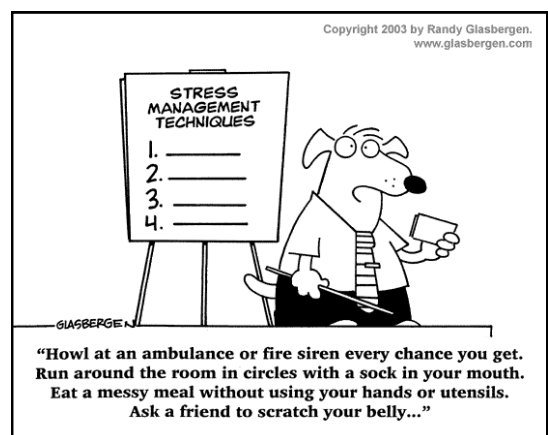
Be Kind to Yourself – You Could Teach Your Kids Something!

You can set a good example for your children by being kind to yourself. Are you curious how you can do that?

Go to <http://creativewithkids.com/5-everyday-ways-to-be-kind-to-yourself-as-a-parent/> to learn how you can make these suggestions for taking care of yourself into teachable moments for your kids.

- Take a stretch break
- Put on lotion
- Take a deep breath
- Find some beauty in each day
- Write in a journal or draw or doodle

In this article they ask a great question. “How will you be kind to YOU today?”





Need Web Assistance?

Many of the articles in this issue of Parent Time refer you to websites. If you do not have access to the Internet, just ask your MoSPIN Parent Advisor to assist you. I am also available to provide information or hard copies of resources. You can contact me at 573-295-4808.

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Halloween Costumes

It is almost Halloween! Do you need ideas for costumes? Go to www.pinterest.com/ginny1396 to see some great ideas for Halloween costumes for kids in strollers or wheelchairs. Other Pinterest boards that you might find interesting at the same link are:

Children with CVI (Cortical Visual Impairment)

Children who are Visually Impaired and their Families

Braille

Orientation and Mobility

Children who are Deafblind



*"I'm thankful for my struggle because without it
I wouldn't have stumbled across my strength."*

- Alex Elle



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